



Maximising sexual wellbeing: The development and evaluation of resources to support men with prostate cancer and their partners

McCaughan, E., Flannagan, C., O'Connor, S., Loughlin, A., & Parahoo, K. (Accepted/In press). Maximising sexual wellbeing: The development and evaluation of resources to support men with prostate cancer and their partners. *Cancer Professional, Autumn*(2020), 1-5.

[Link to publication record in Ulster University Research Portal](#)

Published in:
Cancer Professional

Publication Status:
Accepted/In press: 12/06/2020

Document Version
Publisher's PDF, also known as Version of record

General rights
Copyright for the publications made accessible via Ulster University's Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy
The Research Portal is Ulster University's institutional repository that provides access to Ulster's research outputs. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact pure-support@ulster.ac.uk.

Maximising sexual wellbeing: The development and evaluation of resources to support men with prostate cancer and their partners

Eilís McCaughan, Carrie Flannagan, Sean O'Connor, Anna Loughlin, Kader Parahoo

Background

PROSTATE CANCER is the most commonly diagnosed cancer in Ireland and accounts for almost 30% of the total number of male cancers (excluding the common skin cancer). The National Cancer Registry Ireland estimates annual average incidence of prostate cancer to be more than 3,500 patients in the period 2016 to 2018.¹ While incidence rates are rising, partly associated with improved screening and changes in the population age profile, the 5- and 10-year survival rates continue to improve.^{2,3,4} As a result, increasing numbers of men are living with the disease and with significant, long-term side-effects associated with different treatment approaches.⁵

Sexual challenges (such as erectile dysfunction, reduced libido, dry orgasm and loss of masculinity) are the most frequently occurring long-term symptoms after treatments for prostate cancer.^{6,7,8} In a recent UK-wide survey of more than 35,000 men, more than 80% reported poor sexual function post-treatment.⁹ Evidence states clearly that all men after a diagnosis of prostate cancer should have early and ongoing access to sexual rehabilitation services.^{10,11} However, the recent UK survey stated that nearly 60% of men did not receive adequate information or support to cope with the impact of prostate cancer treatment on their sexual wellbeing.⁹

Changes to sexual function are an effect of all treatments for prostate cancer (surgery, radiation, androgen therapy or combination treatments) and are regarded as a major issue which can result in increased psychological morbidity, including depression and relationship challenges as well as reduction in confidence and overall quality of life [12,13]. Men and their partners have many challenges around their sexual health and wellbeing, following a prostate cancer treatment.^{14,15}

Getting support to manage these challenges may be limited due to fragmented cancer sexual care services within most prostate cancer treatment settings in the Ireland and UK [8,12,15]. To date, there has been an 'ad hoc approach' to the delivery of care, resulting in 'patchy' services and lack of standardised practice. For the few who do receive sexual support, treatment has mainly used a biomedical approach, focusing on erectile dysfunction (ED). Support regarding the psychosocial care including impact on partners is often limited.^{16,17}

Healthcare providers can feel unequipped to deal with sexual health issues and report a lack of resources to support patients

and their partners. There is evidence that men are often reluctant to discuss sexual issues, in particular, those that are seen as sensitive and personal topics.¹⁷ Among the reasons for this is the fear of embarrassment by both men and health professionals (HPs), a lack of HPs knowledge and experience of broaching the topic, and knowing how to offer appropriate support to address patients' psychosexual problems.¹⁸

Many men who are treated for prostate cancer are older and HPs can make wrong assumptions regarding their need for sexual care.¹⁹ Patients are often left in the dark about the possible psychosexual consequences of the different forms of treatment and do not know how, and where, to seek information and support to self-manage their condition. Also, HPs may have limited time available to provide this support.^{20,21}

These challenges may be compounded when HPs work with patients from minority groups, such as single men, black men or men who have sex with men. Many gay men report that HPs fail to ask about sexual orientation during initial consultations and assume they are heterosexual.²⁰ Effective, evidence-based care and support is required to help manage these needs.

Online or web-based interventions can provide access to ongoing, easily accessible information, support and education for users from diverse backgrounds, including HPs and patients. They are also economically sustainable.²² Online resources should not replace face-to-face care, but rather should complement it. For patients, there is evidence that tailoring online support interventions is more effective, with increased user engagement when compared to standardised information.²³

Responding to the need to support men and their partners and to provide training for HPs, TrueNTH (Movember) in collaboration with Prostate Cancer UK, funded a programme of work which resulted in the development of three resources.²⁴ Following training, HPs would provide face-to-face support, routinely in practice, and then signpost men and their partners to an online self-management resource.

The three resources are:

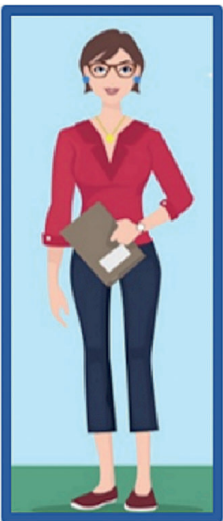
Resource 1: An elearning sexual wellbeing programme for HPs caring for people living with prostate cancer

Resource 2: A framework to guide sexual wellbeing clinical discussions, EASSi

Resource 3: An online self-management sexual wellbeing programme for men and partners living with prostate cancer.

SEXUAL WELLBEING

Figure 1: Summary page for Resource 1: 'Talking about sex after prostate cancer'



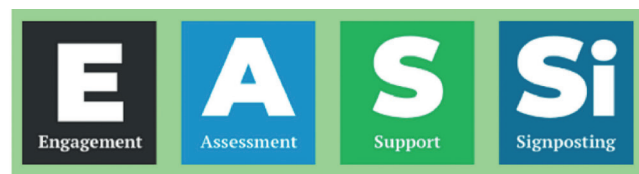
**'Talking about sex after prostate cancer':
an e-learning resource**

Visit: talkingaboutsex-prostatecancer.org

For Healthcare Professionals:

- Provides the **skills** and **awareness** to deliver routine sexual care to men (and partners).
- Provides language, structure and content to guide conversations around sexual wellbeing and prostate cancer
- Can be used as an information resource
- Includes CPD Certificate, 2 learning hours credited

Figure 2: Illustrated EASSi Communication Framework

**Development and evaluation of three resources**

The initial development of the sexual wellbeing resources was informed by a review of the relevant literature on men's, partners and the HP's perspective of their psychosexual needs, and qualitative interviews and focus groups with more than 80 men and their partners, and 27 HPs with clinical experience in this area.

All three sexual wellbeing resources were carefully constructed, tested with user groups (125 users involved) and further refined over an 18-month period. This was followed by formal evaluation with HPs, patients and partners. Although the three resources can be used separately, they have been designed to be interrelated and reflect both the training needs of the HPs and the need to provide self-management strategies to men being treated for prostate cancer, and their partners.

From January 2020, in collaboration with the Irish Cancer Society and Urology team, St James's Hospital, we modified the resources (developed for the United Kingdom population) for use in an Irish context.

The resources*Resource 1: 'Talking about sex after prostate cancer'*

Available from: <https://talkingaboutsex-prostatecancer.org>

This is an e-learning programme designed for all HPs who provide support for men and their partners living with prostate cancer

(Figure 1). It aims to:

- Increase awareness of sexual care needs and the role of HPs
- Promote routine sexual care conversation, as part of the consultation
- Provide strategies to guide conversations around sexual wellbeing and prostate cancer
- Introduce a standard communication framework [Resource 2, EASSi Framework]
- Signpost men (and partners) to appropriate specialist services.

Evaluation of Resource 1

Completion of the e-learning module by 103 HPs resulted in significant changes in positive attitudes and beliefs around sexual wellbeing in prostate cancer care. After working through the module, the participants felt more equipped with the language to initiate conversations. They viewed the resource as clear and concise, and described it as relevant and useful in their practice. The challenge will be to ensure that the strategies and techniques provided in the e-learning module become embedded in routine, standardised practice when caring for all men and their partners coping with prostate cancer.

Resource 2: EASSi Framework

Available from: <https://eassclinic.lifeguidewebsites.org>

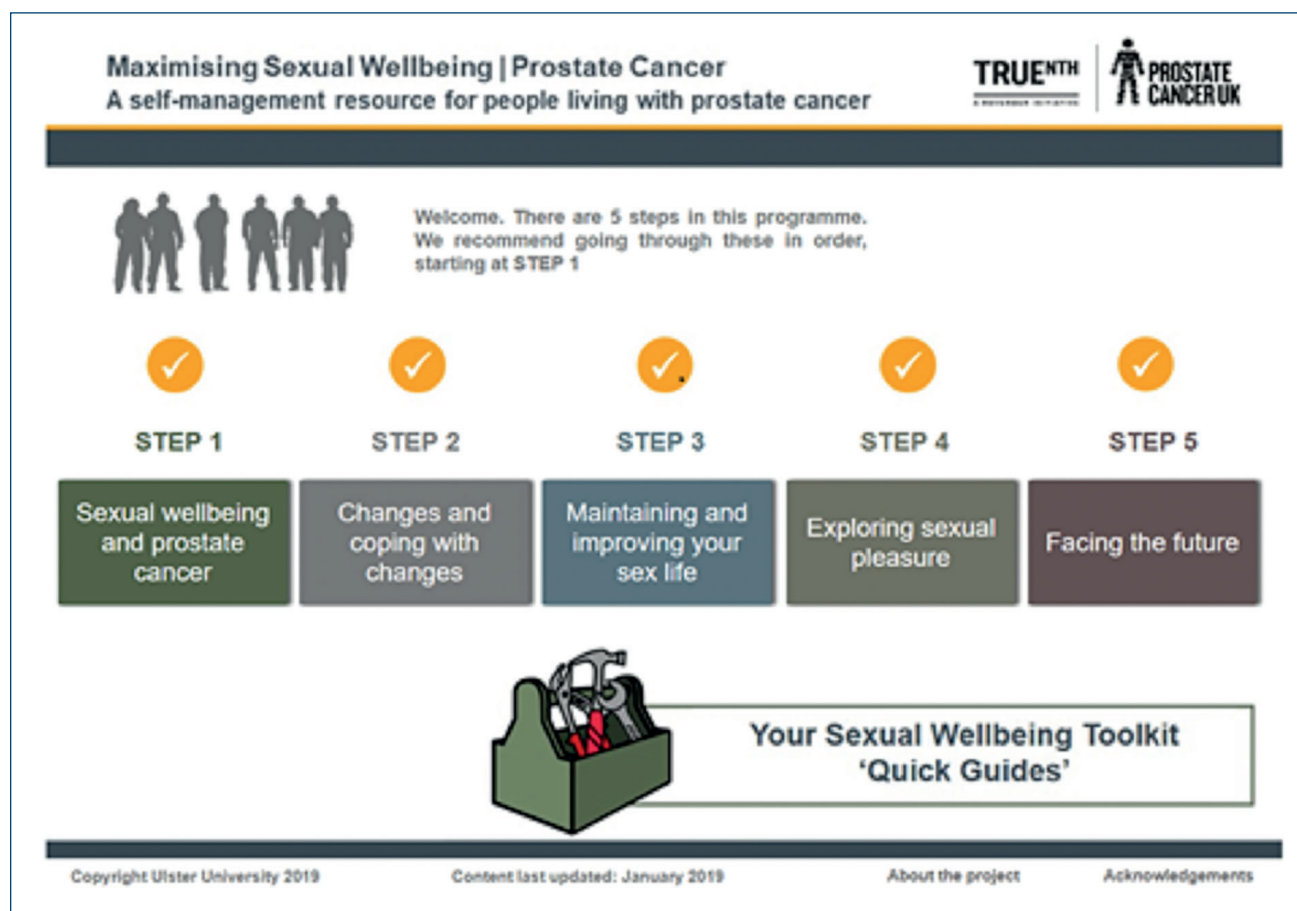
Based on previous work it was recognised how difficult it can be for HPs to talk about sex with patients.¹⁷ There appeared to be a need for a 'framework' to facilitate sexual wellbeing discussions routinely in the clinical setting.²⁵

The 'Engagement, Assessment, Support and Sign-posting [EASSi] programme', a communication framework for HPs, was developed (Figure 2). This framework is designed to be used during routine appointments. It provides the language, structure and content to help guide brief but meaningful conversations about sexual wellbeing with men and partners.

Evaluation of Resource 2

SEXUAL WELLBEING

Figure 3: Main menu page, Resource 3: Online self-management resource



The EASSi Framework was tested in clinical areas using the hand-held tablet, and a shared screen between HPs and patients/partners. Using a mixed-methods approach, the experience of using the EASSi Framework in routine practice was explored after nearly 90 consultations. The EASSi Framework helped initiate, manage and structure discussions. HPs and the patients reported that it added depth to the conversation, while still managing to keep it brief.

Resource 3: Online self-management sexual wellbeing programme

Available from: prostateireland.lifeguidewebsites.org

This is a web-based programme that provides personalised information, support and, to help men and partners, cope with the sexual challenges associated with treatment for prostate cancer (Figure 3). Key features of the online sexual wellbeing self-management programme include:

- Personalised for men and partners (based on treatment, relationship status and sexual orientation)
- It can be accessed at any time-point, before, during, after treatment
- Men and partners to select and view content as required
- It includes specific information for targeted populations including black men, single men, trans women and those receiving palliative care
- Adapted for a Republic of Ireland population

Evaluation of Resource 3

The online recruitment for Resource 3 resulted in more than 250 registered users from around the UK [February 2019 – December 2019].

There were significant improvements in the:

- extent to which participants agreed that they had sufficient information to manage the impact of prostate cancer on their sex life [mean difference 0.78/4; $p = 0.001$]
- perceived potential to have a satisfying sex life following treatment [0.26/4; $p = 0.001$].

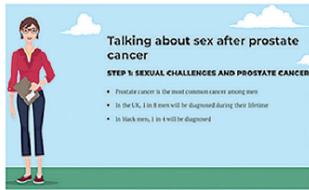


Qualitative data showed that users found the resource an effective way to provide men and their partners with the information and support they needed to address the impact of prostate cancer treatment on their sexual wellbeing. The flexibility of the programme, with a tailored approach to make the information relevant for a mixed population in terms of treatment, sexual orientation and relationship status, was a positive feature that improved accessibility and user engagement. Providing practical information and advice, coupled with a wider approach to sexual satisfaction, were effective ways in which to improve the users outlook on their sexual wellbeing going forward.

Conclusion

There is an increasing number of men experiencing sexual challenges post treatment for prostate cancer. Partners' sexual lives are also impacted. These issues are not routinely addressed and men are dissatisfied with the support they receive. Sex is perceived as a

SEXUAL WELLBEING

Figure 3: Main menu page, Resource 3: Online self-management resource

McCaughan E [Chief Investigator], O'Connor SR, Flannagan C, Wittmann D, Jain S, Thompson S, Maguire R, Connaghan J, Ellis S, Steele M, Kirby M, Davidson G, Bathie G, Nabi G		
'Talking about sex after prostate cancer': e-learning resource for healthcare professionals (HP)	Engagement, Assessment, Support and Sign-posting resource [EASSI]	Online self-management resource for people living with prostate cancer
Visit: talkingaboutsex-prostatecancer.org	Visit: eassiclinic.lifeguidewebsites.org	Visit: prostateireland.lifeguidewebsites.org
What is it? e-learning resource: <ul style="list-style-type: none"> Increases awareness of sexual care needs and HP role Promotes routine sexual care engagement Provides language, structure and content to guide conversations around sexual wellbeing and prostate cancer Introduces EASSI framework [Resource 2] Takes 60-minutes to complete and can be used as information resource 	What is it? Tablet-based programme delivered in clinical area: <ul style="list-style-type: none"> Facilitates routine sexual care discussions with all men (and partners) who are living prostate cancer Designed to normalise sexual issues Provides brief, personalised information and support based on treatment and relationship status Sign-posts to appropriate resources (e.g. Online self-management support programme [Resource 3], ED clinics, Cancer Nurse helplines) 	What is it? Online programme: <ul style="list-style-type: none"> Provides personalised self-management strategies (based on treatment, relationship status, sexual orientation) to help improve sexual wellbeing after prostate cancer Includes support for partners/single/young/black men and those receiving palliative care Includes videos from men, partners & HP's Can be accessed pre-treatment, post-treatment and beyond Can also be used as an information resource
Who is it for? <ul style="list-style-type: none"> HP's who provide routine support for men and their partners living with prostate cancer. For example, nurses, doctors, allied health professionals. 	Who is it for? <ul style="list-style-type: none"> HP's who provide routine support for men and their partners living with prostate cancer For use in clinical setting (primary and secondary) 	Who is it for? <ul style="list-style-type: none"> For men (and partners) who are seeking support and education regarding sexual wellbeing following treatment for prostate cancer. The online resource will be undertaken in the person's home.
		

This work is funded by the November Foundation, in partnership with Prostate Cancer UK, as part of the TRUE programme. © Copyright Ulster University 2019

difficult topic to discuss and HPs appear ill prepared to deliver this care. It is essential that psychosexual care is normalised and integrated within routine practice and that men (and partners) have access to the support they need to ensure they achieve a satisfying sex life. The provision and evaluation of these three resources have shown that they can help to provide this important support.

Ellis McCaughan is a Professor of Cancer Care, Institute of Nursing and Health Research (INHR), and **Carrie Flannagan** is Project Manager, INHR, at Ulster University, Jordanstown, Northern Ireland (NI), **Sean O'Connor** is a Research Fellow, Centre for Public Health, at Queen's University Belfast, NI, **Anna Loughlin** is a Clinical Nurse Specialist – Prostate Cancer Survivorship, SACC Directorate, at St James's Hospital, Dublin, and **Kader Parahoo** is Research Director, INHR, Ulster University

References

- National Cancer Registry Ireland, Annual Statistical Report, November 2018. Available from: <https://www.ncri.ie/data/incidence-statistics>
- Pishgar F, Ebrahimi H, Saedi Moghaddam S, et al. Global, regional and national burden of prostate cancer, 1990 to 2015: results from the global burden of disease study. *J Urol* 2018; 199: 1224–1232
- Miller KD, Nogueira L, Mariotto AB, et al. Cancer treatment and survivorship statistics. *CA Cancer J Clin* 2019; 69: 363–385
- Irish Prostate Cancer Outcomes Research (IPCOR), Annual Report 2018. Available from: <https://www.ipcor.ie/wp-content/uploads/2019/01/>

IPCOR_Annual-Report2018_Digital_NEW.pdf

- Donovan JL, Hamdy FC, Lane JA, et al. Patient-reported outcomes after monitoring, surgery, or radiotherapy for prostate cancer. *N Engl J Med* 2016; 13: 1425–1437
- Gaither TW, Awad MA, Osterberg EC, et al. The natural history of erectile dysfunction after prostatic radiotherapy: A systematic review and meta-analysis. *J Sex Med* 2017; 14: 1071–1078
- Brundage M, Sydes MR, Parulekar WR, et al. Impact of radiotherapy when added to androgen-deprivation therapy for locally advanced prostate Cancer: long-term quality-of-life outcomes from the NCIC CTG PR3/MRC Pro7 randomized trial. *J Clin Oncol* 2015; 33: 2151–2157
- Dyer A, Kirby M, White ID, et al. Management of erectile dysfunction after prostate cancer treatment: cross-sectional surveys of the perceptions and experiences of patients and healthcare professionals in the UK. *BMJ Open* 2019; 9: e030856
- Downing A, Wright P, Hounsborne L, et al. Quality of life in men living with advanced and localised prostate cancer in the UK: a population-based study. *Lancet Oncol* 2019; 20: 436–447
- National Institute for Health and Care Excellence. Prostate cancer: diagnosis and management. Clinical guideline [NG131]. May 2019. Available from <https://www.nice.org.uk/guidance/ng131>.
- Kirby M, White I, Butcher J. Development of UK recommendations on treatment for post-surgical erectile dysfunction. *International J Clin Prac* 2014; 68: 590–608
- Gavin A, Drummond F, Donnelly C, et al. Patient-reported 'ever had' and 'current' long-term physical symptoms after prostate cancer treatments. *BJU Inter* 2015; 116: 397–406
- Sanda MG, Dunn RL, Michalski J, et al. Quality of life and satisfaction with outcome among prostate-cancer survivors. *N Engl J Med* 2008; 358: 1250–1261
- Guercio C, Mehta A. Predictors of patient and partner satisfaction following radical prostatectomy. *Sex Med Rev* 2018; 6: 295–301
- Drummond F, Gavin A, Sharp L. Incongruence in treatment decision making is associated with lower health-related quality of life among prostate cancer survivors: results from the PICTURE study. *Supp Care Cancer* 2018; 26: 1645–1654

SEXUAL WELLBEING

16. Bamidele O, Lagan B, McGarvey H, et al. 'It might not have occurred to my husband that this woman, his wife who is taking care of him has some emotional needs as well...': the unheard voices of partners of Black African and Black Caribbean men with prostate cancer. *Supportive Care in Cancer* 2019; 27: 1089-1097
17. O'Connor S, Connaghan J, Maguire R, et al. Healthcare professional perceived barriers and facilitators to discussing sexual wellbeing with patients after diagnosis of chronic illness: A mixed-methods evidence synthesis. *Pat Edu Coun* 2019; 102: 850-863
18. Dyer K, das Nair R. Why don't healthcare professionals talk about sex? A systematic review of recent qualitative studies conducted in the United Kingdom. *J Sex Med* 2013; 10: 2658-2670
19. Reese JB, Sorice K, Beach MC, et al. Patient-provider communication about sexual concerns in cancer: a systematic review. *J Cancer Surviv* 2017; 11: 175-188
20. Kotronoulas G, Papadopoulou C, Patiraki E. Nurses' knowledge, attitudes, and practices regarding provision of sexual health care in patients with cancer: critical review of

- the evidence. *Support Care Cancer* 2009; 17: 479-501
21. King A, Evans M, Moore T, et al. Prostate cancer and supportive care: a systematic review and qualitative synthesis of men's experiences and unmet needs. *Eur J Cancer Care* 2015; 24: 618-634
22. McAlpine H, Joubert L, Martin-Snaches F, et al. Systematic review of types and efficacy of online interventions for cancer patients. *Pat Edu Coun* 2015; 98: 283-295
23. Corbett T, Singh K, Payne L, et al. Understanding acceptability of and engagement with web-based interventions aiming to improve quality of life in cancer survivors: A synthesis of current research. *Psycho-Oncology* 2018; 27: 22-33
24. Movember Foundation. Available from: <https://truenth.org/en-gb/>; <https://uk.movember.com/about/prostate-cancer> (Accessed May 2020)
25. McCaughan E, Parahoo K, Flannagan C et al. Development of a conceptual framework to improve sexual wellbeing communication in routine prostate cancer care. *Pat Edu Coun* 2019 (In press)